

Rachel Quade Presents at National Ticket to Work Summit

Rachel Quade, a young adult with Williams Syndrome who resides in Boise, recently returned from Atlanta Georgia, where she represented Idaho and her cohorts at the historic Beneficiary Summit “Voices for Change: Paving the Way to Work.” The Summit, by order of the President of the United States, marked the first-ever opportunity for beneficiaries of disability payments, to provide comprehensive input on the hurdles and barriers encountered, and establish incremental steps to remove the hurdles and barriers to obtaining sustainable employment. Rachel was able to attend the conference, at the invitation of the SSA, due in a large part to the tremendous support of her personal assistant Vori Shewfelt, and her Community Based Transition teachers, Carol Carnahan and Jennifer Comstock.

Rachel's Summit Report:

In order to make sure that I do not leave out any details, I have asked my personal assistant, Vori Shewfelt, to assist me in recording my story. In December, 2006 I was selected to attend the Beneficiary Summit “Voices for Change: Paving the Way to Work .” As part of my self-advocacy goals through the Boise School District's Community Based Transition Program, Carol Carnahan, devoted teacher, encouraged and helped me apply to be a delegate at the summit. In the application I promised to interview my peers before the summit so as to better represent my population of Social Security beneficiaries, attend the summit and advocate for my peers, and then upon returning home educate people about my experience.

The purpose of the summit was (1) to develop recommendations on incremental improvements to existing programs, (2) to compile information on beneficiaries' experiences and the obstacles they have encountered in pursuing work and the major focus of the summit (3) to create a permanent process for Social Security beneficiaries to have a prominent voice in SSA legislation, rules, and implementation.

To my joy and excitement I was chosen to represent Idaho and my population of Social Security beneficiaries. The summit took place at the Marriot Marquis in Atlanta, GA February 6th and 7th. The SSA had chosen a delegate from each state and US territory to represent the entire population of Social Security beneficiaries. The SSA paid for

our travel arrangements, hotel accommodations, and even gave us provisions for food. The trip was so exciting and I was very happy to be there representing Idaho and my population of beneficiaries.

The Ticket to Work Panel had put a lot of work into organizing the summit. They came up with four themes: Overall Theme: *Raising the Beneficiary Voice*, Theme #1: *Employment and Work Incentives*, Theme #2: *Health Care and Long Term Services and Supports*, and Theme #3: *Improving Program Communication, Procedures and Service Delivery*. Every delegate was involved in making recommendations for the first theme of Raising the Beneficiary Voice, but could choose to take part in two of the three remaining theme areas. The panel also broke the theme areas up into different workgroup sessions. In Theme #1 the workgroups were: Session 1A – *Ways to Improve Current SSA Programs and Work Incentives*, Session 1B – *Proposal for a New “Work Support Program”* and Session 1C – *Employment for Youth with Disabilities and Adults with New Disabilities*. Theme #2 was broken into: Session 2A – *Medicare, Medicaid, and Private Health Insurance*, and Session 2B – *Long Term Services and Supports, Including Personal Assistant Services*. Theme #3 was broken into: Session 3A – *Getting the Right Information to the Right People at the Right Time*, Session 3B – *Improving Service Delivery to Beneficiaries: How the Program Works in the Real World*, and Session 3C – *Improving Interaction between SSA and Other Programs*.

I chose to take part in Workgroup Sessions 1C and 3A. Each delegate chose two workgroup sessions that they wanted to attend. The main focus in Workgroup 1C was making the transition from school to work easier for youth. Some of the major issues identified in Youth finding employment are:

- Parents' dependence on SSI
- Transportation to and from work
- Lack of SSA assistance in finding jobs
- Segregation in schools
- Lack of employer awareness
- Lack of opportunities for training
- Lack of supports to obtain and retain work
- Increase training requirements for Personal Assistants
- Lack of advocacy and information in schools
- Lack of information on options after school
- Lack of student input into IEP process

Low expectations from schools, VR and society
Avoidance of expensive programs by VR and inadequate funding for VR

The recommendations made were all focused on bridging these barriers. We recommended:

“No Child left Behind” should really mean NO child left behind. We encouraged schools to be held accountable for the outcome of every student, regardless of their disabilities. Schools should be graded on how well they place their special education students either into further education or into a job placement.

Provide information to parents and students on rights and responsibilities

IEP and VR training for students and parents

Training by youth for youth, expand peer programs in schools

Expansion of services in rural areas

Fix performance measures for VR counselors especially working with youth with severe disabilities

Funding for youth training for independent living skills and support (Independent living centers)

My workgroup selected one of the delegates in the session to present our recommendations to the entire group of delegates at the summit. We chose Raphael, a young man with a developmental disability and a degree in Business, to present our recommendations. Raphael, unfortunately, has had trouble finding employment because of his disability, even though he has Business degree. All of the workgroups chose a delegate to present and we heard the recommendations made by every workgroup.

Workgroup Session 3A – Getting the Right Information to the Right People at the Right Time, also put forth some very important recommendations. The main barrier we identified was simply the lack of education of available programs to Social Security beneficiaries and also their care providers. I am a participant in a Developmental Disabilities Agency and only one employee in the agency had heard of the “Ticket to Work” program upon my selection as a delegate at the summit. Also, I sent out questionnaires to Idahoans who receive SSI and only one person who responded had heard of and was actively using the “Ticket to Work” program. Teachers in Transition Programs are also uninformed about the available programs. How can the SSA

expect the beneficiaries to understand and use the programs if nobody tells them? The official recommendations made by all of the delegates are:

Empower beneficiaries by making SSA policies and procedures easier to find, easier to understand and available in accessible formats. Minimize SSA “speak” and use plain language that all can understand. Materials should be reviewed by a diverse ethnic and disability committee. Veterans should be able to receive SSDI and veterans’ benefits without one offsetting the other.

I volunteered to present my workgroup’s recommendations to the entire group of delegates. My personal assistant had to help me read the big words, but it was a lot of fun and everybody clapped for me. I love advocating for myself and my peers.

Due to the expensive amount of recommendations made to the SSA for each theme area we ended up doing “dot polling” to vote on the issues most important to us. Most of the issues most important to me and my population of beneficiaries were not voted on as extensively because adults with developmental disabilities were not as strongly represented at the summit. It seemed that there were only a couple delegates with significant developmental disabilities that would prevent secondary educational opportunities at the summit representing the entire population for whom work opportunities will probably be limited to minimum wage jobs. There was a feeling that the “Ticket to Work” program does not apply as strongly for adults with developmental disabilities because it is doubtful that I, and my beneficiary population, will be capable of working above the level of substantial gainful employment. My recommendation is if the “Ticket to Work” program does not apply to me, then please make a program that does. I am capable of working. I want to work. I like to earn money and I should be able to do so without fearing losing my benefits. All young adults with developmental disabilities should be informed about their right to work without losing their benefits.

The overall summit theme of Raising the Beneficiary Voice was very productive. We decided that every beneficiary should have the opportunity to give feedback on Social Security programs. Who knows the pitfalls and successes of SSA programs better than the people that live in the programs everyday? The recommendations made by my group were:

Communication Plan

- ListServ
- Press Release
- Teleconferences
- Organize the disability community
- “One Voice”
- Cross-disability
- Contact Decision Makers
- Congress
- SSA
- White House

This was such an amazing opportunity for me, personally, for the SSA receiving honest feedback, and for the other beneficiaries involved. I am optimistic that this summit was just the first step in the process of making positive changes happen. I want to thank my family, Developmental Concepts Inc., Boise Schools— my teachers Carol Carnahan, and Jennifer Comstock, my classmates and friends, and a special thanks to my extra special friend, advocate, and personal care provider Vori Shewfelt for their unending support in my quest and development of self-advocacy skills. It is through advocacy and strengthened self-advocacy that I, and other beneficiaries will bring a strong Voice for Change. Thank you to the President for recognizing the needs of young persons with developmental disabilities!